293 The CF family/teen teaching day – do the benefits outweigh the risks?

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Providing up to date information and answering questions is key to empowering teenagers with Cystic Fibrosis and their family. Regular CF teaching days have previously been run on a yearly basis to help meet these needs at the Hospital for Sick Children. When infection control and the need to cohort CF patients became evident, the teaching days were stopped – but not forgotten.

In 2006 the CF team ran a joint parent/teen education day, including lecture format in the morning for both groups, and an informal teen group run by our adolescent medicine specialist and social worker for the afternoon. Infection control measures were carefully followed. No patients with *B. cepacia* or MRSA were invited. A large well ventilated classroom was used and the teens sat 4 feet apart. Tissues and alcohol hand wash were placed throughout the room. All teens had sputum sent for analysis before, and 3 months after the day. None have had new acquisition of bacteria to date. Seventy teens (age 12 and over) were eligible and invited to the day, and eleven attended (16%). All were given volunteer hours for the day.

Evaluations by the parents were 91% positive for the information lecture style format. In contrast only 55% of the teens evaluated the information sessions as positive, but over 85% responded positively to the teen only session with informal discussion.

In conclusion, with careful infection control measures in place, a CF teaching day can be run with relatively low risk of cross infection, and enormous benefits as evidenced by the overwhelmingly positive response from the parents. The teens were more receptive to group work with their peers, and attendance was contingent upon a reward system, such as volunteer hours. Positive outcome from the day include a CF specific online chat room being established.

294* West Midlands cystic fibrosis (CF) newborn screening training evaluation

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The National Screening Committee recommended the introduction of Universal Newborn Cystic Fibrosis Screening as part of the existing newborn blood spot test. Implementation of this new programme in the West Midlands commenced on 1st November 2006 following the delivery of comprehensive regional training.

The aim of this project was to develop a training programme to ensure standardised delivery of information to relevant health care profesionals.

The training was co-ordinated by a CF nurse specailist and a child health co-ordinator who adapted the national training package to meet the West Midlands specific needs. Included in this package was an educational day for the team of trainer's, development of a training CD Rom, speakers notes, handouts, advertisement and co-ordination of the sessions.

A team of trainers consisting of Cystic Fibrosis Nurses, Genetic Counsellors, Newborn Screening laboratory personnel and the Child Health Screening Co-ordinator were recruited and delivered a total of 72 one hour training sessions across the West Midlands between 1st September 2006 and 15th November 2006. Approximately 719 health professionals attended. The training sessions were held at the local maternity units, community clinics and primary care training departments. Invitations were extended to midwives, health visitors, obstetric, paediatric and neonatal staff.

The training sessions evaluated positively and the educational package has now been assimilated into the newborn blood spot screening programme.

The above represents an evaluation of a seamless multi professional and multi centre project.

295 Parents' perceptions and recommendations for follow-up of newborn screening

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Newborn screening for CF began in the Calgary Health Region in May 2005 as a pilot study. To date, 23,664 infants have been screened with 58 recalled for a sweat chloride. Research has shown that newborn recall can be an anxiety provoking experience for parents. A survey was mailed to parents whose infants had been contacted between June 2005 and December 2006. The purpose of this survey was to evaluate procedures for contacting parents and recalling infants. Questions focused on the parents' knowledge of the screen, feelings, decisions about genetic counselling, aspects of the experience that were problematic or helpful, and recommendations. Twenty-one of the surveys were returned. Parents (52%) reported being unaware of the screen. They described feelings such as shock and fear with the initial phone contact. Parents (57%) preferred to hear results from a CF specialist. After the initial telephone contact, 85% of parents agreed that they felt prepared for the recall appointment. They reported satisfaction with the (1) length of the appointment with the CF specialist; (2) information provided; (3) support from healthcare professionals; and (4) opportunity for follow-up. They also expressed the desire for more information to be provided by prenatal caregivers and emphasized the need to minimize the waiting time for a sweat chloride test and follow-up appointment. Contacting parents with newborn screening results can create distress. Parents want information and timely follow-up. Knowledgeable and responsive healthcare professionals, who listen to parent questions and concerns, can reduce the impact of this potentially adverse experience. These findings are important in the development of a newborn CF screening program.

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296 Can computers improve the in-patient experience? A survey of patients' views

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Cystic Fibrosis patients are at risk of cross infection through social contact with each other. Unit policy is that patients are segregated throughout their time on the ward. In-patient admissions typically involve around two weeks stay: patient feedback highlighted feelings of boredom and isolation when confined to their rooms. The Unit's response was to introduce computers for patients to use. Each room is equipped with a computer with internet acess. Patients can keep in contact with each other by web cam.

A year after this facility was introduced, we conducted a survey of patients' views. A random sample was drawn from records of admissions and questionnaires were mailed out, resulting in a 41% response rate. Responses were predominately very postive: 85% used the computer facilities and 86% of these said this had helped them cope with their stay in hospital.

Patients used a range of computer functions. Passing the time in hospital was the greatest benefit cited, closely followed by keeping in contact with friends and family to combat isolation. Patients also stated that they had been able to keep up with their college work or employment, manage their financial affairs and seek information about health matters. Overall, introducing the computers has been an initiative that patients value as improving the quality of their experience in hospital.